Spotlight on Advocacy…Alliance for Childhood Cancer

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The Alliance for Childhood Cancer (ACC) (http://www.allianceforchildhoodcancer.org/) was established in September, 2001 to bring together patient advocacy groups within the medical and scientific community. This collaborative work is intended to advance the needs of pediatric oncology patients in the areas of education, diagnosis, treatment and research. A listing of the member organizations can be found at: http://www.allianceforchildhoodcancer.org/memberorgs

The American Academy of Pediatrics has been a member organization of this group since its inception with representation through a pediatric hematology/oncology liaison and the AAP Department of Federal Affairs staff. Dr. Edwin Forman, MD FAAP, a founding member of the ACC, has served as the liaison on behalf of the Academy and the Section on Hematology/Oncology (SOHO) for the past 10 years. I have assumed this role as of, August 1, 2014 and had the opportunity to participate in several meetings in Washington, D.C. on behalf of the Academy during September and October, 2014.

The annual Congressional Childhood Cancer Summit was held on September 19, 2014 at the U. S. Capitol Visitor Center and was led by Dr. Frances Collins, Director of the National Institutes of Health (NIH). Later that day, a White House briefing on pediatric cancer was held at the White House Executive Office Building and was led by the Office of Public Engagement with Dr. Harold Varmus, Director of the NCI as the keynote speaker. Finally, a policy roundtable was held by the ACC on September 20, 2014.

Below is a summary of the discussion items raised throughout the two day event:

Increasing Funding for Pediatric Cancer Research
The White House Chief Officer of Management and Budget indicated difficulties in recommending additional allocations toward the NIH and suggested the Department of Defense (DOD) as a potential additional funding stream. The Director of Congressionally Directed Medical Research for the DOD (COL Wanda Salzer) was supportive of this concept. Dr. Collins cited a decrease in overall NIH funding, encouraged support from the ACC and recommended discussion with the National Cancer Institute (NCI) to enhance the fundability of pediatric-focused research. Dr. Varmus (NCI) indicated that funds are allocated according to the quality and innovation of the proposals rather than in a disease or age specific way.

Promoting Legislation that Enhances Pediatric Research
• Possible revision of existing laws including the Best Pharmaceuticals for Children Act and Pediatric Research Equity Act.
• The Carolyn Price Walker (CPW) Act is in need of renewal and appropriation which is predicted to be difficult. The ACC is looking to increase sponsorship for CPW. The Gabriella Miller Act was mentioned in the previous meeting minutes, but was not discussed.
• The Creating Hope Act had its first success with Biomarin and Vimizim.
• 21st Century Cures was mentioned. More information needs to be collected.

Addressing Issues Interfering with Access to Care
• As it is generally accepted that treating children on study is the standard of care, having more available clinical trials would reduce access problems. This is being attempted through the above funding and legislative tactics. The AAP has also re-initiated an effort to gain congressional support directed at the NIH to report the data on the inclusion of children in NIH trials.
• Access to investigational agents via compassionate use and expanded use mechanisms were discussed. Congressman McCaul is seeking input from stakeholders on legislation predicted to be drafted in 2015. This could include (but is not limited to) mandating publicly available criteria for inclusion, incentivizing policy, tracking and reporting mechanisms, and standardization of justifications for denial. The group felt that individual input would be best and the ACC will be available for comment after the draft is complete.
• Availability of FDA approved medication was identified as a risk area for access. Poor access could result from drug

Continued on Page 11
shortages, prior-authorization denials, medication cost, insurance coverage and tiered co-pays. The ACC did not agree this area was a priority for the group, but encouraged individuals interested to continue to work in this area outside of the alliance.

- Access to palliative/end-of-life care, supportive care, and survivorship care were identified as a concern for some members.

**ACTION ITEMS**

1. **Funding Follow-up:** A subgroup, selected by the ACC co-chairs, is organizing a meeting with NCI leadership to discuss opportunities to improve pediatric research funding. The proposed agenda includes discussion on transparency in criteria and process, future research goals, MATCH trial specifics, and suggestions for innovative opportunities.

2. **Develop Alliance Consensus:**
   - Complete governance structure to fill voids in leadership positions within ACC (events, communications and membership).
   - Agree on primary goals which will then trigger specific organizational considerations, identify constituents, allies and opponents, targets and tactics.

3. **Work Outside the Alliance:** Interested individuals will pursue independently or as smaller subgroups work in areas not addressed by the ACC, i.e. compassionate/expanded use, palliative care, payer relations.

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**Advocacy in Action**

**Grassroots Advocacy: AAP Key Contact Program**

Key Contacts are AAP members who are interested in receiving advocacy opportunities and timely policy updates from the AAP Department of Federal Affairs on federal legislation and other issues important to the Academy.

Through regular e-mail communication with specific requests for action, the Department of Federal Affairs keeps Key Contacts informed of the latest legislative developments affecting children and pediatricians.

**How to Become a Key Contact:**

E-mail kids1st@aap.org with your name, AAP ID if known, and your preferred e-mail address. If you have questions about federal advocacy, contact AAP Department of Federal Affairs at 800-347-8600.


Visit the AAP Department of Federal Affairs website at [FederalAdvocacy.aap.org](http://www.FederalAdvocacy.aap.org) to find federal advocacy resources and tools, including:

- Contact and biographical information for your federal legislators
- An Action Center where you can call and e-mail federal legislators directly on current federal child health policy priorities
- Information on how to submit timely opinion pieces to local media outlets
- Fact sheets on health reform implementation and other timely topics
- All recent federal testimony given by AAP experts before the U.S. government on various child health topics
- Additional online resources such as PowerPoint presentations, videos, and other documents on current federal child health policy priorities.

**Save the Date: Legislative Conference 2015**

The AAP Legislative Conference will be held April 12-14, 2015, in Washington, DC. Participants will have the opportunity to develop their federal advocacy skills through interactive workshops, learn about timely child health policy topics, hear from several guest speakers from Congress and the Administration and visit with their legislators on Capitol Hill. If you are interested in attending and would like to be notified when registration opens, please email LegislativeConference@aap.org. For more information, please visit [aap.org/legcon](http://aap.org/legcon).